study (Keding, et al. 2012 Psycho-Oncology 21:13-14) 2) service evaluation in 3 regional HSCT centres (84 participants in 8 professional groups).

*Phase two:*ALLINEX development & beta testing. Web-site content was designed by health & psychosocial care specialists in response to the outcomes of Phase I. Local & national information resources were used to provide content. Beta testing in patients (23), HSCT staff (24) & family doctors (3) drove iterative development culminating in a final design for use in phase three.

Phase three: A randomised pilot study recruited patients <2.5y post-HSCT with predicted minimum review of 2 clinic visits within 12 weeks of informed consent. Stratified randomisation (with/without Graft versus Host Disease) allocated participants to SC or SC plus ALLINEX. Patient reported outcomes including HADS, SDI-21 & EORTC QLQ-C30 were collected at baseline & 12w post consent. Patients in the intervention arm completed questionnaires on Patient Acceptance & Use of Technology at 6w, ALLINEX feedback & system usability scale at 12w & had website activity tracked. All clinic visits were audio-recorded for simple content analysis & additional contacts logged.

Results: Services evaluation identified gaps in service (e.g. limited psychological support), standard services (e.g. open access to transplant team) & reactive services (e.g.referrals to psychiatry). Consequently, ALLINEX included information in 5 domains ranging from "everyday living" to "end of life," an interactive patient forum & a messaging system for contacting the HSCT team. Beta testing resulted in minor amendments.

Phase three recruitment was completed September 2012 with a participation rate of 71% & 50/53 patients completing the study. Analysis is ongoing (due completion December 2012).

Conclusions: Involvement of patients & staff at all stages of ALLINEX development has resulted in a website that performed well in preliminary testing. Initial analysis indicates that the site is relevant, accessible & comprehensive. Final analysis may lead to changes in ALLINEX, guidance training for patients & staff & further development of the interactive aspects of the site.

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Fatigue: A Long Standing Symptom Affecting Quality of Life in Patients Following Hematopoietic Cell Transplantation

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Objective: Hematopoietic stem cell transplantation (HSCT) is a potentially curative therapy for malignant and autoimmune diseases. As the scope of transplant expands treatment for more diseases and patient types, quality of life (QOL) specifically fatigue, will remain an important measure for outcome and long term survival in HSCT. Overall QOL is reported to return to baseline or exceeds baseline by one year while fatigue remains a major symptom that is long lasting as far out as 10 years.

Methods: A Pub Med search was completed in 2009 using mesh terms, HSCT, bone marrow transplant, and quality of life. This resulted in one hundred and seventy nine articles. When fatigue was added to the mesh terms the number of articles dropped to eleven. Highly relevant references were chosen from articles and books. The National Comprehensive Cancer Network (NCCN) website was also used as a source for cancer related fatigue.

Results: Long term follow up studies of HSCT patients as far out as ten years report fatigue as high as 35%. In comparative trials with healthy controls this has been shown to be statistically significant. Multiple reasons may exist for this prolonged decrement including chronic graft versus host disease, preparative regimens, treatment prior to HSCT and underlying disease. No studies to date have determined the underlying etiology of long standing fatigue. Small studies with exercise interventions and cognitive behavioral therapy show promising results. These types of treatment may have an impact on patients with fatigue following HSCT.

Conclusion: Multidimensional scales have been used to measure fatigue in many QOL studies but few to date have used fatigue specific scales. Multimodal interventions have been shown to decrease the loss of aerobic fitness, muscle strength, and functional performance. Interventions with exercise in addition to behavioral therapy with objective physical measures and fatigue measurement scales may be beneficial in determining the cause of this chronic symptom in patients post HSCT.

Multi-item measures commonly used in QOL assessments in HSCT

Measure Name	Purpose	Domains	No. of items	No. of item assessing fatigue	Reliability
Functional Assessment of Cancer Therapy, Bone Marrow Transplant (FACT- BMT)	HSCT patients specific QOL	Physical, social, functional, emotional wellbeing with BMT symptom scale Gives total score	47 items total Likert scale	2 items	Cronbach alpha .52-. 85
European Organization for the Research and Treatment of Cancer Quality of Life Questionnaire Cancer (EROTC)	General Measure QOL in cancer	Physical, social, role, cognitive, emotional, Symptoms Scales: fatigue, pain, nausea/vomiting; Global health/QOL scale Domain and Total scores	30 items total Likert scale and yes/no	3 items	Cronbach alpha .54-.86
Medical Outcome Study SF-36	General Measure in QOL in healthy and medicine populations	Physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional, mental health composite scores of physical and mental domains	36 items total Likert scale and yes/no	4 items	Cronbach alpha .63-.94

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A Systematic Review and Meta-Analysis of Changes in Cognitive Functioning in Adults Undergoing Hematopoietic Cell Transplantation

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Background: Evidence is mixed regarding the effects of hematopoietic cell transplantation (HCT) on changes in cognitive functioning among adults. Meta-analysis may help reconcile conflicting findings but has not yet been conducted with this literature. The current study provides a systematic review and meta-analysis of cognitive functioning in adults receiving HCT.
Methods: A search of PubMed, PsycInfo, CINAHL, and Cochrane Library yielded 732 abstracts, which were independently evaluated and selected for inclusion by pairs of raters. Original studies of neuropsychological functioning in HCT recipients who were adults at the time of transplant were included in the systematic review (k=17). A subset of studies assessing patients pre- and post-transplant and providing adequate data to calculate effect sizes was included in the meta-analysis (k=11).
Results: The systematic review found consensus that a subset of patients experience cognitive impairment prior to HCT. Evidence was conflicting about whether cognitive functioning improved, declined, or remained stable at follow-up. Meta-analytic findings of 404 patients indicated no significant changes in cognitive functioning pre- to post-HCT ($ps>.05$). Age, time since transplant, and total body irradiation were not associated with changes in cognitive functioning. Patients who received autologous transplants were more likely to demonstrate improvements in attention ($p=.004$), however.
Conclusions: Results of the current study suggest that on average, patients who are experiencing cognitive difficulties prior to HCT are unlikely to demonstrate significant improvement post-transplant, with the exception of improved attention in autologous HCT recipients. The failure of HCT patients to demonstrate improvements over repeated tests may itself be a sign of a deficit, as improvement due to test familiarity would be expected. Patients reporting cognitive difficulties that interfere with daily functioning should be referred to a neuropsychologist for evaluation and management.

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Quality of Life Following Allogeneic Hematopoietic Cell Transplant: What Patients Wish They Had Known

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Background: Quality of life is increasingly recognized as one of patients' primary concerns and an important clinical endpoint of hematopoietic cell transplant (HCT). Although a growing body of research has examined change in quality of life during the transplant process, the extent to which these data have been incorporated into patient education is unclear. The goal of the current study was to examine education regarding post-HCT quality of life from the patient's perspective.
Methods: Men and women who had received allogeneic HCT two to four years previously participated in one of four qualitative focus groups based on a semi-structured interview guide. Participants were asked to recall what they had been told about post-HCT quality of life as they were deciding to undergo the transplant, how their current quality of life differed from what they expected, and how to best educate future HCT recipients about quality of life. Verbatim transcripts were coded for a priori and emergent themes using content analysis.
Results: A total of 24 patients participated (54% female, mean age 51, range 23-73). Regarding patient education, most participants noted that they had been told about potential side effects of HCT and behavioral and dietary restrictions, but little about quality of life. Many reported actively trying to avoid information about HCT pre-transplant and instead focused on surviving the procedure. Participants often reported that their post-HCT quality of life fluctuated, which was contrary to their expectations regarding sustained improvement. Participants widely agreed that patient education regarding quality of life should occur throughout the transplant process. They emphasized that the ability to control the amount of information was important, as was hearing about quality of life from other patients.
Conclusions: These data suggest that patient education regarding post-HCT quality of life could be improved. Educational materials that are tailored to patients' information preferences, can be used throughout transplant and survivorship, and feature other HCT recipients are preferred.

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The Effect of Exercise Compliance in Patients Undergoing Hematopoietic Stem Cell Transplantation on Their Functional Capacity During Their Hospitalization

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Purpose/Hypothesis: To examine the impact of an in-patient exercise program of participants undergoing hematopoietic stem cell transplant (HSCT) on functional capacity, and to compare the relationship between exercise compliance and incidence of exercise-related adverse events. The goals are 1) to examine the feasibility of tracking outcomes of an exercise program in patients undergoing HSCT on their functional capacity, and 2) to examine the association between exercise compliance and exercise-related effects in patients with severe pancytopenia within this patient cohort.
Materials/Methods: 30 adult participants were recruited during their inpatient hospital stay. Participants completed the short form Physical Activity Questionnaire (PAQ), 6-minute walk test and 5-times-repeated-sit-to-stand test at time of transplant and 12-14 days post-transplant. Participants instructed in a multimodal intervention to include aerobic (walking or stationary bike), resistance (resistance bands), and active range of motion exercises. Exercise compliance was measured by the patient's exercise log. Incidence of hemorrhagic events and platelet levels were collected. This research consisted of a one group pre-test/post-test study design with consecutive sampling over an estimated nine month span (recruitment to be finished by October 2012). Descriptive statistics will be used to describe functional capacity trends from pre and post-test measurements, to examine patient's functional capacity from start and end of study. This study will be utilizing a post hoc analysis to further investigate compliance and differences on functional capacity measures by subgroups. Will also determine the relationship of the incidence of exercise-related pancytopenia events over 14 days and percent exercise compliance rate, controlling for confounding factors.
Results: We anticipate that participants performing the prescribed exercise program will have improved functional capacity. We expect no difference with higher exercise compliant participants in incidence of hemorrhagic events as